Service design for children and young people with common mental health problems: literature review, service mapping and collective case study

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Dedication

In memory of Hannah Welsby, who was the study advisory group's young person co-chair at the study's inception. Shortly after the advisory group's inaugural meeting, at which Hannah proved to be an exceptional co-chair, we were saddened to hear of her death. We are grateful for the passion, leadership and humour that Hannah brought to the study. Her family are rightly proud of her contribution to this study and her other patient and public involvement (PPI) activities.

Disclaimer

This report contains transcripts of interviews conducted in the course of the research, or similar, and contains language which may offend some readers.

Scientific summary

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Background

This study is a response to a National Institute for Health and Care Research (NIHR) commissioning call on research to improve services for children and young people (CYP) with common mental health problems (CMHPs).

The mental health of CYP has been a growing public health concern both nationally and internationally. Estimates from 2021, covering the height of the coronavirus disease 2019 (COVID-19) pandemic, suggest that around one in six CYP in England may be experiencing significant mental health difficulties, including the likes of anxiety, depression, self-harm and behavioural difficulties.

The tiers model has dominated UK service provision for at least two decades. However, it has become increasingly clear that this model has not met the needs of most CYP experiencing mental health problems. Numerous reports and reviews have consistently described UK children's mental health services as fragmented, unco-ordinated, variable, inaccessible and lacking an evidence base. While there have been recent attempts to transform services using initiatives such as Choice and Partnership Approach (CAPA), Children and Young People-Improving Access to Psychological Therapies (CYP-IAPT) (a CYP's version of adult IAPT) and THRIVE, little is known about the effectiveness of these initiatives nor the effectiveness of children's mental health service models in general. Moreover, the disparate factors associated with accessing and navigating services for CYP experiencing CMHPs have not been synthesised into a coherent model of effective and acceptable service provision.

Aims and objectives

The study's overarching aim was to develop a model of high-quality service design for CYP experiencing CMHPs by identifying available services, the barriers and enablers to access, and the effectiveness (including cost effectiveness) and acceptability of, those services. Six objectives were derived from this aim:

1. Systematically search, appraise and synthesise the international literature on services for this population group in order to (1) build evidence of the effectiveness and acceptability of current service provision and (2) assist with objective 2.
2. Develop a descriptive typology of services for this population group using the literature referred to in objective 1 and a survey of service provision in England and Wales.
3. Through primary research, explore the barriers and enablers that CYP and their families experience in accessing and navigating services.
4. Identify the key factors influencing effectiveness and acceptability in order to build an evidence-based model of high-quality service provision for this population group.
5. Estimate provider and user costs/benefits associated with different service models.
6. Make evidence-based recommendations to the NHS about future service provision.

Methods

The study coupled evidence syntheses with primary research, using a sequential, mixed-methods design. There were four work streams: (1) conducting a scoping review and an integrative review of the international literature; (2) mapping service provision across England and Wales; (3) conducting a

collective case study of several services in England and Wales; and (4) building a model for high-quality service design for CYP experiencing CMHPs.

Patient and public involvement

We involved young people and parents/carers, as well as those who commission and provide mental health services throughout the study. Young people and parents/carers were members of the study's advisory group and the director of a young people's 'lived experience' consultancy was a coinvestigator. We also collaborated with a mental health charity to employ six young adults with lived experience of mental health issues as 'young co-researchers'.

Work Stream 1 (literature reviews)

Data sources

Relevant bibliographic databases and resources (including grey literature resources) were searched in May 2019.

Study selection (inclusion criteria)

Population

Children and young people was defined as those aged under 18 (service users up to 25 years could be included if a service's core provision was for under 18s). Common mental health problems were defined as anxiety and related disorders, depression, self-harm, post-traumatic stress disorder (PTSD), 'emerging personality disorder', adjustment disorder, attention deficit hyperactivity disorder (ADHD)/attention deficit disorder, conduct disorder, oppositional defiant disorder, substance misuse disorders and 'at risk of psychosis'. The commissioning brief excluded psychosis, eating disorders and autism spectrum disorder.

Interventions

Any service provided for CYP experiencing CMHPs.

Comparators

Not applicable for the scoping review or the acceptability data in the integrative review. For the effectiveness and cost-effectiveness data in the integrative review, comparators were other service models, standard care/treatment as usual or inpatient/residential care.

Outcomes

Not applicable for the scoping review. Outcomes for the effectiveness data in the integrative review were relevant measures of CYP's mental health, family functioning, educational attainment or quality of life; for the cost-effectiveness data, the incremental cost effectiveness of service model versus comparator; for the acceptability data, qualitative and quantitative data capturing stakeholder views.

Study (document) types

For the scoping review, any document containing a sufficiently detailed description of a service for CYP experiencing CMHPs. Effectiveness studies in the integrative review were peer-reviewed quantitative studies with at least one pre/post outcome measure; cost-effectiveness studies were peer-reviewed studies reporting costs, health outcomes and incremental cost-effectiveness analyses; acceptability studies were peer-reviewed qualitative or quantitative studies in which either participants' views were expressed or in which participation data were available.

Data extraction and quality assessment

For both reviews, two independent assessors extracted data. Disputes were referred to a third reviewer. Quality assessment was conducted for the integrative review only, using the Mixed-Methods Appraisal Tool (MMAT).

Data synthesis

In the scoping review, descriptions of services for CYP experiencing CMHPs were mapped into a typology of service models. Synthesis in the integrative review was based on Evidence for Policy and Practice Information and Co-ordinating (EPPI)-Centre methods: the different data sources (effectiveness, cost effectiveness and acceptability) were analysed separately prior to being compared and contrasted.

Work Stream 2 (service mapping)

Data sources

Services across England and Wales were identified via an online survey created in SelectSurvey and internet (desk-based) searches. English or Welsh services identified through the literature search and still in operation were also included.

Service selection (inclusion criteria)

The same population and intervention definitions as Work Stream 1 were used. Additional inclusion criteria were the service had to operate in England or Wales and be operational during the data collection period.

Data analysis

On closing the online survey, data were downloaded from SelectSurvey in Microsoft Excel format. Additional data (e-mail submissions and desk-derived information) were inputted into the same Excel spreadsheet by hand. A final Excel spreadsheet containing both survey and desk-derived data was imported into IBM SPSS Statistics for descriptive analysis of service characteristics.

Work Stream 3 (case study)

Design

A collective case study involving nine services sampled from the service map. Services were purposively sampled to capture the spread of models in the typology and to reflect characteristics such as service sector, locality/setting, target age group and mode of delivery.

Participants

Ninety-six interviews involving 108 participants (41 CYP, 26 parents, 41 staff) from 9 case study sites.

Research ethics

Ethical and other approvals were granted by the NHS Health Research Authority (reference: 20/SC/0174) and by the organisations operating the services at the case study sites. Four substantial and two minor amendments, all relating to the COVID-19 pandemic, were subsequently approved.

Data collection

Original data collection plans included individual interviews, focus groups, documentary review and observation of relevant activities at sites. Coronavirus disease 2019 restrictions, however, prevented site visits and observation. Consequently, the primary data (apart from one interview) were collected remotely, either through individual semistructured telephone or video interviews or an online group interview. Twenty-two of the 96 interviews were jointly conducted with 1 of our 6 young co-researchers.

Economic data were requested from sites regarding annual service delivery budgets, funding source, key areas of spending and resource use.

Data analysis

Data analysis was informed by framework, a matrix-based analytic method widely used in qualitative health service research. To familiarise themselves with the data, the research team read and discussed

the interview transcripts in depth. The transcripts were then coded deductively in NVivo using a thematic framework based on the study's aims and objectives, after which the data were 'charted' so that deductive codes for each theme could be examined within each case study site and comparatively across sites. The data were then analysed inductively and iteratively to identify cross-cutting themes. Cost data were descriptively summarised into a table.

Work Stream 4 (model building)

Data synthesis process
The integrative review and case study findings were synthesised using the 'weaving' approach to integration through narrative. The two sets of findings were analysed, interpreted and reported together on a theme-by-theme or concept-by-concept basis using a set of mixed-methods matrices.

Results

Work Stream 1 (literature reviews)
Overall, 310 documents met the inclusion criteria for the scoping or integrative review. Two hundred and ninety-six documents were included in the scoping review, 98 in the integrative review.

To simplify the complexities associated with fragmented, variable and often unco-ordinated services, the 342 service descriptions in the 296 scoping review documents were mapped to produce a descriptive service model typology containing seven broad service model groupings. Across the international literature, the service models most described in the scoping review documents were outreach models, followed by community-embedded specialist CAMHS models. Service transformation frameworks were also relatively common.

The integrative review found effectiveness evidence only for collaborative care, outreach approaches, brief intervention services and 'availability, responsiveness and continuity (ARC)', a service transformation framework from the USA. The strongest effectiveness evidence was for collaborative care. Cost-effectiveness evidence was very limited (just three papers met the inclusion criteria), with the only robust evidence also being for collaborative care. Since most of the collaborative care evidence was from the USA, its applicability to UK health systems is questionable. No service model appeared to be more acceptable than others. Integrative review findings suggest that effective and acceptable services tend to be underpinned by few barriers to access, interagency working, the use of consultation-liaison and consideration of the service's culture. Brief intervention approaches may be helpful in managing waiting lists; their brief nature may also facilitate the acquisition of self-management skills.

Work Stream 2 (service mapping)
One hundred and fifty-four services across England and Wales, provided by 123 different providers, were included in the service map.

Service provision across England and Wales is diverse, with providers from the statutory, private and third sectors operating in a range of settings, supporting CYP with a wide range of CMHPs. No single model from the typology was particularly dominant. Most services were provided in community, non-health settings, most focused on secondary school aged children and most offered support for the 'most common' of the CMHPs, namely general anxiety issues, depression and self-harm. Open access via self- or parent referral was relatively widespread, particularly in the third and private sectors.

Work Stream 3 (case study)
Three themes emerged from the case study data: *pathways to support* (relates to service access and exit); *service engagement* and *learning and understanding*.

Regarding the enablers of and barriers to service access, self-referral, the timeliness and availability of support, physical accessibility and planning for support following discharge are important determinants of whether a service is seen as accessible by CYP and families. A single point of access (SPoA) to services may be beneficial if it does not result in multiple assessments or multiple waiting lists.

The service engagement and learning and understanding themes highlighted the importance of personalised, holistic and flexible services that involve CYP and families, respect confidentiality, ensure continuity in therapeutic relationships, focus on strengths and engage CYP in creative ways. Staff expertise and professional competence are important but so are empathy and compassion. An organisational learning culture appears fundamental to service acceptability and effectiveness: it was important for staff to work in environments that emphasised staff learning and development, supported reflective practice and which valued service improvement especially when CYP and families were able to co-design services. Service effectiveness was also linked to opportunities for CYP to develop knowledge and skills that enabled them to both understand and manage their own mental health.

Work Stream 4 (model building)

With feedback from relevant stakeholders (including CYP, parents, service providers and academics from a range of relevant disciplines), the three narratives around *pathways to support*, *service engagement* and *learning and understanding* were integrated to create an alternative model of effective and acceptable services for CYP experiencing CMHPs. This evidence-based model outlines the fundamental components necessary for high-quality services for this population group. These fundamental components include information, confidentiality, aftercare, personalised approaches, engagement and organisational culture.

Conclusions

In a robust and transparent way, we have developed a comprehensible, evidence-based model of high-quality service design for CYP experiencing CMHPs that is transferable across services, sectors and geography. Our model has utility for policy, practice and research. Not only does it support previous research and reports about children's mental health services, but it also adds significant depth to core issues surrounding mental health service provision for CYP.

In terms of implications for policy, practice and education, our research suggests that:

- Using our model components to support the design and delivery of services – rather than the 'top–down' imposition of specific local or national models – could improve the consistency of services for CYP experiencing CMHPs. Our model still allows for tailoring to the local context.

We also note that:

- Aftercare arrangements are often neglected (especially for those aged 16–17 years), not just in terms of transitions to adult services but also in terms of exiting and re-entering a service, longer-term ad hoc support and continuity of care.
- A learning culture strongly implies services need more than mere staff training. Workforce development requires strategies that incorporate reflexive learning opportunities, clinical supervision, reflective practice, freedom to innovate in practice and leadership.
- CYP and families need to be the arbiters of what compassion and competence in staff mean.
- Lived experience in service provision is valuable, but it may work better when delivered alongside professional support.

- More information about what services are available locally, how services might be accessed, what support is offered and what happens once the CYP leaves the service should be provided.
- CYP and their families want to be able to choose, ideally from a range of services, those best tailored to their needs.

In terms of future research, there should be:

- research focusing on how to implement into practice the components in our model
- research determining whether using our model to design, deliver or audit services impacts on outcomes
- research exploring the advantages and disadvantages of digital/remote platforms in delivering services
- research around what the statutory sector could learn from the non-statutory sector regarding choice, personalisation and flexibility
- research with those who refuse and/or disengage from services and others whose voices are seldom heard
- further research on the cost effectiveness of different approaches in CYP's mental health
- research to establish one or more standardised measures of health benefit in children's mental health services.

Study registration

This study is registered as PROSPERO CRD42018106219.

Funding

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